

## Time to tackle stigma

*'Stigma, silence, discrimination and denial, as well as a lack of confidentiality, undermine prevention, care and treatment efforts and increase the impact of the epidemic on individuals, families, communities and nations and must be addressed.'*

Declaration of Commitment on HIV/AIDS, **Global Crisis - Global Action.**

INCREASING ATTENTION is being paid to the role of stigma as a major contributory factor in the global HIV/AIDS pandemic. Stigma associated with HIV/AIDS is especially powerful and pervasive because the disease is usually closely associated with such fundamental issues as life and death, sex and sexuality, and morality.

*'It is the combination of these issues, together with their intensity, that makes it so difficult for those affected to overcome the impact of HIV/AIDS-related stigmatisation,'* says Dr Cosmas Musumali, Health Policy Advisor, Zambia Integrated Health Programme (ZIHP).

Stigma associated with HIV/AIDS is particularly damaging because it often impacts upon the poorest and most vulnerable individuals and groups in society, many of whom are already disadvantaged and discriminated against on other grounds – for example women, orphans and vulnerable children, sex workers, men who have sex with men, gay men and injecting drug users.

Stigma at a societal level can lead to silence and denial – a refusal to acknowledge and deal with HIV/AIDS. This reinforces ignorance and fear, allowing prejudice to thrive, risky behaviour to go unchallenged and uncaring behaviour to go unchanged. It also ensures that some of the key stakeholders in the response to HIV/AIDS, people living with HIV/AIDS (PLHA) and their families, remain silenced and side-lined.

The impact of stigma on the individual can be experienced in two distinct ways, **felt** and **enacted**.

Felt stigma relates to feelings. Individuals often feel stigmatised or are fearful that they will be stigmatised. This can profoundly affect their self-esteem, their views and how they relate to others.

Enacted stigma relates to experiences. Individuals can be denied access to information, health

services, company and the support they need. They can also face loss of job, compulsory testing, even violence and quarantine. These experiences contribute to a climate of fear where people are afraid to discover, let alone disclose, their HIV status. This proves a major barrier to effective prevention, care and support.

The challenge now is to reduce stigma and deal with the many and severe problems that it causes. The following articles look at ways in which this is possible, both at community and national level.



Despite the availability of counselling, the three clients of this NGO, based in Maharashtra, India, remain fearful of being identified and stigmatised. This picture was taken with informed consent.

<b>HASAB (HIV/AIDS/STD Alliance – Bangladesh)</b>	<b>Grupo Pela Vidda Grupo de Incentivo a Vida</b>	<b>IPC (Initiative Privée et Communautaire Contre le SIDA au Burkina Faso)</b>	<b>KHANA (Khmer HIV/AIDS NGO Alliance)</b>	<b>Corporación Kimirina</b>	<b>India HIV/AIDS Alliance</b>
Bangladesh	Brazil	Burkina Faso	Cambodia	Ecuador	India
hasab@bdmail.net	gpwvj@pelavidda.org.br giv@osite.com.br	ipcsida@cenatrin.bf	khana@bigpond.com.kh	kimirina@ecuanex.net.ec	allianceindia@vsnl.com

## Viewpoint

# Mongolian Sex Workers Tackle Stigma and Discrimination



## Viewpoint: By Altantsetseg Batsukh, Program Manager at the National AIDS Foundation (NAF), Mongolia

*Addressing stigma plays a central role in a programme for sex workers supported by the Alliance linking organisation in Mongolia, the National AIDS Foundation (NAF). Based in Darkhan, this programme was initiated by the Darkhan Women's Council, an NGO established in 1950 to build women's capacity and improve their health and social status and to establish legal empowerment of women through advocacy.*

Darkhan is Mongolia's second largest city with significant mobility to and from other provinces in Mongolia and to areas of high HIV incidence in neighbouring countries via the Trans-Siberian railway. Commercial sex takes place in and around the railway station and in bars and small hotels throughout the city. With temperatures as low as -45°C and limited access to shelter, water and appropriate working spaces, sex workers are vulnerable to a range of illnesses and injuries, violence and to demands for unprotected sex.

These issues were explored in a participatory community assessment that identified the attitudes of health workers, police and society in general as contributing significantly to the conditions that render sex workers vulnerable and limit their access to health care, appropriate working spaces and human rights. Interestingly, during the assessment, sex workers raised how they "buy in" to the stigma with their own sense of guilt and disgrace and how that affects their social relations.

As a result of the assessment, DWC designed and implemented a project to build solidarity amongst sex workers as well as to influence key policies, practices and attitudes that

affect the sex industry. Facilitated discussion groups amongst sex workers were followed up by a series of meetings where sex workers expressed their views to the Mayor, senior police, health workers, railway officials and local bar owners.

As a result of the project, sex workers reported a greater sense of cooperation with key authorities, improved attitudes and decreased stigma, increased access to health care, improved police responses to violence and harassment and more access to condoms and water.

As an example, one small but important change is that sex workers can now access health services anonymously. Perhaps most importantly, sex workers report a general sense that they can have some influence over their conditions rather than accepting unfair and substandard circumstances.

The improved relationship between police and sex workers is striking, with the sex workers' drop-in centre operating a few feet from the police post — with its full support and co-operation. This improvement coincides with a dramatic decrease in the incidence of STIs among the sex workers who use the centre.

Some links between stigma and sexual health are clear and observable. With a greater understanding of sex workers' lives, the local health care providers recognised the need to apply their rules more appropriately to enable sex workers to access their services. Police ceasing the common practice of confiscating condoms as evidence of prostitution is another clear link.

It is crucial that we develop better ways to understand and challenge the impact of stigma on HIV prevention and care efforts. This is particularly urgent where there is political and social pressure to bring about behaviour change and better health-seeking behaviours among stigmatised groups. This will be difficult to achieve without addressing their stigmatised status or challenging the way they are treated by those who are not similarly stigmatised.

Colectivo Sol	NAF (National AIDS Foundation)	AMSED	PHANSuP (Philippines HIV/AIDS NGO Support Program)	ANCS (Alliance Nationale Contre le SIDA)	Ukraine HIV/AIDS Alliance
Mexico	Mongolia	Morocco	The Philippines	Senegal	Ukraine
colsol@laneta.apc.org	www.naf.org.mn naf@magicnet.mn	www.maghrebnet.net.ma amsecpassida@am.net.ma	phansup@info.com.ph	ancs@enda.sn	www.aidsalliance.kiev.ua office@aidsalliance.kiev.ua

## Communities in Action

# Overcoming stigma

REDUCING THE STIGMA EXPERIENCED by people living with HIV/AIDS is key to developing effective prevention and care responses. Drawing on the Alliance's field programme experience, we have identified a number of strategies to help address stigma at a community level as well as through broader changes in public policy.

### ✓ Provision of community-based programmes which empower marginalised populations

The provision of visible care and support programmes within the community can in itself be an effective way to reduce stigma and discrimination. An NGO working with sex workers in rural India recounted a villager's comments:

*"We didn't want to help people with AIDS because we were afraid, but when we saw strangers doing what we should have done ourselves we were ashamed. Now we help each other."*

IWAG-Davao, an NGO supported by PHANSuP, the Alliance linking organisation in the Philippines has been running community development projects with men who have sex with men. These projects include organising cultural activities during local festivals, community clean up campaigns, and conducting regular hair-cutting days for free. These activities have helped minimise discrimination against gay men or men who have sex with men in the village.

*"...In the past...the gays here were thought of as frivolous, or only concerned with fashion, but having this recognition from the village council has made the organisation much more prominent and promoted others to join...and now younger boys, some of them not yet in high school, are coming to us for advice – some parents are also more resigned to the fact that a child might be homosexual, and some ask about the best way to relate to their children who are gay,"* said an IWAG staff member.

### ✓ Greater involvement of people living with HIV/AIDS (PLHA)

The findings of a study on community level involvement of PLHA in four countries, indicated that involving PLHA in prevention, care, support and advocacy can lead to improved access to care and support and reduced stigma and discrimination. In Burkina Faso, a group of NGOs identified the following strategies to promote the involvement of PLHA in care and support:

- Provision of support and education in dealing with stigma and discrimination
- Raising awareness among testing and care workers so that they can help clients anticipate these situations
- Guaranteeing confidentiality to people with HIV so that they can decide whether or not to disclose
- Support groups for people with HIV
- Sensitising non-infected workers in relation to their attitudes toward people with HIV

*"Some of us got involved in HIV/AIDS activities as a way to show other people that we are entitled to do the same things as the rest of humanity. I have the same rights to work, make love, have children as anybody else... but we still have a long way to go before positive people are perceived as 'normal' people."* Alé Trosserro, Programme Officer for Latin America, International HIV/AIDS Alliance.

### ✓ Policy measures

The Alliance programme in Zambia ran a public attitude survey to assess the prevalence and types of stigma in local communities. This information will be used to guide future policies and stigma reducing strategies in care and prevention programmes.

### Lessons learned - Uganda

The example of Uganda shows that a policy and practice of openness can have a catalytic effect, starting a chain reaction that reduces stigma and eventually also the prevalence of HIV. The openness in Uganda was a result of three main driving forces:

- Political leadership at the highest levels
- A social climate in which civil society organisations were able to flourish
- Community initiative

This helped to generate innovative ideas for dealing with stigma. It also led to stronger commitment and increased human, financial and material resources for HIV/AIDS programmes from all major stakeholders.

ZIHP – SERV (Zambia Integrated Health Programme)	Alliance Zambia	FACT (Family AIDS Caring Trust)
Zambia	Zambia	Zimbabwe
andrewm@zihp.org.zm	allza@zamnet.zm	rgp@aloe.co.zw

## News Update

### New Field Office in Zambia

A new Alliance field office, Alliance Zambia, has opened in Lusaka. Alliance Zambia will be giving financial and technical support to eight intermediary organisations in Zambia, who will, in turn, be supporting local NGOs and CBOs to carry out HIV prevention, care and support and impact mitigation programmes. Alliance Zambia will also be granting money directly to local NGOs and CBOs. This initiative will complement the Alliance's ongoing collaboration within the Zambia Integrated Health Programme (ZIHP).

### Launch of the Stop AIDS Campaign

On 28 November 2001, the "Stop AIDS Campaign" was launched in the UK. This is a new initiative for greater UK and international action on global HIV/AIDS. The Campaign is calling on the UK government to show ever stronger political commitment and take an international lead in fighting the epidemic – including pledging a five-fold increase in resources devoted to tackling the crisis. The Campaign will also work with other groups to tackle critical issues such as debt burden, which continues to divert vital resources away from health care, health systems and education, and the lack of affordable medicines to treat HIV/AIDS and the opportunistic infections it causes. You can visit their website at: [www.stopaidscampaign.org.uk](http://www.stopaidscampaign.org.uk)

### Nigerian Presidential Support

The President of Nigeria, Olusegun Obasanjo, has given his personal backing to the new Alliance programme in Nigeria.

### Madagascar

A one-year programme of technical support to eight service-delivery NGOs has been completed and they will now

receive funds to conduct HIV prevention and STI treatment activities as part of the new Alliance multi-country prevention programme in conjunction with the Bill and Melinda Gates Foundation.

### Ethiopia

The Alliance is working with two PLHA groups to help them refine their strategic and action plans, identify their technical support needs and assess their role in the national response to HIV/AIDS. This will be followed by a PLHA workshop for NGOs that are integrating HIV/AIDS into their programmes.

### South and East African Regional OVC Workshops

The Alliance and FACT (based in Zimbabwe) held a workshop on expanding support to community orphans and vulnerable children (OVC) initiatives in southern and eastern Africa, which was attended by 25 participants from key OVC support providers in the region.

### Exploratory Assessment visits in China

The Alliance undertook an exploratory situation assessment visit to Beijing and three provinces in China (Guangji, Yunnan and Xinjiang) and will follow up with further identification of partners and strategy development for technical support to southern China in 2002.

### New Trustees

The Board of Alliance trustees is to welcome three new members: **Bai Bagasao**, formerly Founding Chair of the Board of PHANSuP and now Director of Partnerships at UNAIDS. **Peter Freeman**, CBE, has recently retired from DFID where he held a number of senior positions including Director, Multilateral Aid, Director for Africa and Director, Finance and Aid Policy. **Beatrice Were** is from

Uganda and living openly with HIV. She was Director of the National Community of Women Living with HIV/AIDS in Uganda (NACWOLA) for six years before taking up the post of Executive Co-ordinator at the International Community of Women living with HIV (ICW) in the UK.

### Supporters:

The Alliance has received a US\$25 million award from the Bill and Melinda Gates Foundation for a five-year programme. This will provide intensive support to community level programming to slow the spread of HIV in Cambodia, Ecuador, India and Madagascar. The Alliance will develop policy and good practice to promote prevention with key populations in low prevalence countries.

The Alliance has also received \$355,000 from the DFID's Civil Society Challenge Fund for support to Mongolia and US\$190,000 from the Swedish International Development Agency for Africa regional support.

KHANA, the Alliance linking organisation in Cambodia, has received \$200,000 from the Japan Intentional Cooperation Agency (JICA) for a three-year programme to strengthen the capacity of NGOs responding to HIV/AIDS care and support.

### Recent Publications and Resources:

- **Documenting and Communicating HIV/AIDS Work: a Toolkit to Support NGO/CBOs** aims to promote the value of good documentation and communication, build practical skills and encourage organisations to share their experiences and lessons learned with others. Available in French in 2002.

- **A Facilitators' Guide to Participatory Workshops with NGOs/CBOs Responding to HIV/AIDS** – a practical resource for those facilitating participatory workshops and meetings. It draws on the combined experience of many facilitators worldwide. Available in French and Spanish in 2002.

- **A Handbook on Access to HIV/AIDS Related Treatment. A Collection of Information, Tools and other Resources for NGOs, CBOs and PLHA Groups** – to help groups that are considering getting involved in treatment and care, as well as groups that are newly involved in treatment and care.

- **Scaling-up Training for HIV/AIDS Community Initiatives in Eastern and Southern Africa** – a report of a workshop jointly held by the Alliance and the Regional AIDS Training Network (RATN).

- **An Introduction to Promoting Sexual Health for Men Who Have Sex with Men and Gay Men** – a training manual developed by the Naz Foundation (India) Trust with support from the Alliance. For use by South Asian NGOs working with MSM.

View and download Alliance publications from the Alliance website [www.aidsalliance.org](http://www.aidsalliance.org) and the Alliance partner website [www.aidsmap.com](http://www.aidsmap.com).

*Our thanks to Dr Cosmas Musumali for his valuable insight and contributions to this newsletter.*

Printed on 100% recycled paper.

International HIV/AIDS Alliance  
Queensberry House  
104-106 Queens Road  
Brighton BN1 3XF  
United Kingdom  
Tel: +44 1273 718 900  
Fax: +44 1273 718 901  
E-mail: [mail@aidsalliance.org](mailto:mail@aidsalliance.org)  
Web sites: [www.aidsalliance.org](http://www.aidsalliance.org)  
[www.aidsmap.com](http://www.aidsmap.com)

